

rado and should be verified using data from other States.

Finally, and most important, the case mix and quality data used only suggest the four conclusions listed previously. More detailed patient-specific data on activities of daily living scales, severity of patients' problems and diagnoses, and quality of services provided (even outcomes, if possible) are needed to make the implications of this paper conclusive.

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## An Assessment of the Completeness of the Massachusetts Burn Registry

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## SYNOPSIS

*An opportunity to assess the completeness of reporting to the Massachusetts Burn Registry arose*

*when data on the incidence of inpatient burns in Massachusetts became available from an independent source, the New England Regional Burn Program. The assessment showed that the level of reporting to the registry was approximately 20 percent and that substantial geographic variability existed. Other areas in which the registry is experiencing difficulties that bear on its potential usefulness include confusion about the type of burns that are reportable, lack of adequate control of data quality, and insufficient funds to support the registry's activities. Continuation of the present burn reporting system does not seem defensible in the absence of changes in either the reporting requirements or the reporting methods, because the level of reporting is low, the quality of the data is unknown, and the registry is not achieving goals of substantial public health importance.*

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**B**URN INJURIES IN THE UNITED STATES account for the deaths of approximately 6,300 persons each year; an additional 60,000 persons are hospitalized annually for the treatment of burns. Among the industrialized nations, the United States has the highest death rates and per capita property loss from fires (1). Our undesirable position has persisted for several decades notwithstanding improvements in medical care for burned patients and a greater recog-

nition that burns are a largely preventable public health problem.

A fairly recent approach to the control of burn injuries has been the establishment of statewide and national registries of burns. One example is the Massachusetts Burn Registry, which was established by law in 1973 to provide a data base from which information on the incidence and epidemiology of burns statewide could be obtained (2). Reportable

burns were defined in the 1973 law as burns affecting 5 percent or more of the surface area of a victim's body. Less extensive burns were excluded from the reporting requirement to eliminate the need for clinicians to report the numerous burns affecting less than 5 percent of the surface area of a person's body, and thus to make reporting manageable. According to the law, reports must be made within 15 days after the date of the burn. As a result of this requirement, data are available from the registry on the causes of the burn and the characteristics of the victim, but not on the long-term care and rehabilitation of the burned patient.

From its inception until December 1981, the Massachusetts Burn Registry was located in the division of food and drug of the State department of public health (3). The department provides standardized forms for reporting and compiles monthly summaries of the data for public review. The registry was transferred to the division of family health services on Jan. 1, 1982.

Informal assessments of the completeness of the Massachusetts Burn Registry suggested that many reportable burns were not included in the registry and that the level of reporting varied widely from town to town. Because nearly complete reporting or, in its absence, knowledge of the factors affecting reporting, will to a large extent determine how useful the registry will be, every effort should be made to measure the level of reporting and to institute changes should that level prove to be unsatisfactory (4).

An opportunity to assess the completeness of the registry arose when data on the incidence of hospitalized burns in Massachusetts during 1978 and 1979 became available from an independent source, the New England Regional Burn Program. The results of this assessment are reported here.

### **New England Regional Burn Program**

The New England Regional Burn Program (NERBP) was one of six projects established under contractual agreements with the Division of Emergency Services of the U.S. Department of Health and Human Services (then the Department of Health, Education, and Welfare) to collect data on burn injuries occurring over a 26-month interval—May 1978 to June 1980 (5). The primary objective of these projects was to collect data pertaining to the delivery of medical treatment to burned patients nationwide. It was hoped that these data would (a) permit evaluation of the adequacy of existing

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treatment facilities, (b) provide estimates of the relative effectiveness of different modes of burn care, and (c) identify the cost of the acute care and rehabilitation of burn patients.

Among the NERBP's data collection efforts were: (a) the identification of persons admitted to any of 110 of Massachusetts' 113 acute-care hospitals for treatment of a new burn injury and (b) the identification of persons who had died from burns without receiving medical treatment. Patients were identified primarily by a review of hospital inpatient records and emergency-room logbooks and by a review of the death records compiled by the division of health statistics and research, Massachusetts Department of Public Health. An additional method of identifying burn victims was by review of newspapers and other news reports for mention of burn injuries. All burns treated at participating hospitals, regardless of the percentages of the burned surface area of the victim's body, were included in the study.

To assess the completeness of the NERBP's casefinding, a second casefinding procedure was implemented in a representative sample of participating hospitals. This intensive review indicated that the overall completeness of casefinding was at least 90 percent.

### **Completeness of the State Registry**

The measure of the completeness of the Massachusetts Burn Registry is the average reported number of inpatient burns occurring in 1978 and 1979 divided by the number of inpatient burns identified for a comparable period by the NERBP through its initial casefinding methods. The latter number of burns is the average number of inpatient burns occurring in the 1978 and 1979 May-through-December periods, plus the number of inpatient burns occurring in the period January through April 1979. These numbers of burns were obtained from the interim listing of NERBP data covering the period

May 1978 through December 1979 (the most recent listing available). The NERB listing is at least 90 to 95 percent complete.

The comparison described in the preceding paragraph includes inpatient burns regardless of the extent of the burn. Notwithstanding the requirement that only burns affecting 5 percent or more of the surface area of a victim's body were reportable, approximately 10 percent of the inpatient burns that were reported to the registry affected less than 5 percent of the surface area. The percentage of burns affecting less than 5 percent of the surface area of the inpatients identified by the NERBP is unknown because information concerning the proportion of the body surface burned was recorded in intervals of 10 or 20 percent (the category of the smallest burn being equal to less than 10 percent of a victim's body surface). In a recent, independent study of burns in six Massachusetts communities, 40 percent of the hospitalized patients had burns affecting less than 5 percent of the surface area of the body (6),

a figure compatible with the estimated proportion of 66 percent found by the NERBP for burns affecting less than 10 percent of the body surface (5).

## Results

An average of 250 inpatient burns were reported to the Massachusetts Burn Registry in 1978 and 1979 (272 in 1978 and 227 in 1979). The NERBP identified 1,223 inpatient burns for a comparable period, a figure which suggests that the completeness of the registry for inpatient burns was only 20 percent. (The actual completeness of the registry for inpatient burns may be somewhat higher if, as the percentages cited in the preceding paragraph suggest, the NERBP identified more burns affecting less than 5 percent of the body surface area than were reported to the registry.)

Underreporting was more extensive in the two most heavily populated counties in Massachusetts—Middlesex and Suffolk—than in other counties. The

Number of inpatient burns in Massachusetts by system of data collection, 1977-79

City or town	1977 population	New England Regional Burn Program for 1 year	Massachusetts Burn Registry		
			1977	1978	1979
Boston	618,493	196	39	25	15
Worcester	165,229	68	13	3	3
Springfield	164,895	53	7	9	10
Cambridge	99,296	27	7	3	1
Fall River	98,898	35	10	13	7
New Bedford	98,845	21	3	2	6
Brockton	94,175	26	8	4	1
Quincy	90,571	19	9	8	9
Lowell	88,449	41	3	5	5
Newton	87,183	13	2	1	2
Lynn	77,089	34	11	18	14
Somerville	76,771	23	4	2	3
Framingham	64,079	12	2	4	4
Medford	60,519	5	2	1	1
Chicopee	56,572	13	1	0	1
Weymouth	56,305	6	1	0	4
Waltham	55,632	11	0	0	0
Malden	54,987	4	2	1	1
Pittsfield	52,313	21	1	2	2
Brookline	50,680	13	2	2	1
Total	2,210,981	641	127	103	90

estimated completeness of reporting, based on all inpatients, was 14 percent (39 of 271 burns) for Middlesex County and 10 percent (22 of 219 burns) for Suffolk County.

The number of inpatient burns identified by the registry in 1977, 1978, and 1979 and the number of such burns identified by the NERBP for a 1-year period are shown in the table for 20 of the 21 cities and towns in Massachusetts that had populations of more than 50,000 in 1977 (7). Lawrence, the other city with a population of more than 50,000 in 1977, is not included because the two hospitals primarily serving Lawrence residents did not participate in the NERBP.

As can be seen from the table, in the years 1977-79 combined, the registry identified less than half as many inpatients with burns as were identified by the NERBP in a single year. Also, the table shows substantial underreporting for each of the cities and towns listed. The completeness of reporting to the registry ranged from 0 percent in Waltham to perhaps as high as 67 percent in Weymouth for 1979.

## Discussion

The results indicate that the completeness of the registry for inpatient burns is low. Because approximately 30 percent of reportable burns, including almost all disfiguring or other severe burns, are those of inpatients (6), the underreporting of these burns bears significantly on the overall completeness of the registry. This fact and the geographic variability in reporting just described for inpatients—but which has also been recognized with regard to all reportable burns from the beginning of the registry—severely limit the interpretability and usefulness of the registry data.

Also, in at least four other areas, the registry is experiencing difficulties that bear on its potential usefulness. The first area, which is related to the underreporting of burns, concerns the definition of a reportable burn in the law establishing the registry, namely, one affecting more than 5 percent of a patient's body surface. This definition has caused confusion about the goals of the registry. For example, according to the definition, a mild sunburn on the arms of an otherwise healthy teenager is a reportable burn, whereas a small electrical burn in a child's mouth, a more severe and potentially disfiguring injury, is not a reportable occurrence.

The second area of difficulty is the lack of adequate evaluation and control of the quality of the

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data. The underreporting of cases is one part of the difficulty. Another part is the lack of verification of the accuracy of the information contained in the burn reports. For obvious reasons, such verification should be a routine part of data collection.

A third difficulty is the lack of adequate funding to support the activities of the registry. The acquisition and maintenance of an accurate registry of burns is an expensive undertaking even under the present system in which no one is compensated monetarily for reporting burns. The lack of monies to provide for the feedback of useful information to clinicians is a related problem and one that might lead to a deterioration in the level of reporting.

A final difficulty is the apparent obscurity of the registry. In July 1982, the Governor of Massachusetts signed into law, effective in October 1982, a bill establishing a second statewide burn registry. This law, like the one that established the current registry, requires the reporting of burns affecting 5 percent or more of the surface area of a victim's body. The second registry will be located in the State fire marshal's office, department of public safety. According to the bill's sponsor, no mention was made of the present burn registry during the legislature's hearing on the new law (8). In an era of rising costs and increased use of health care services, the establishment of a second statewide burn registry, identical to the first one in terms of reporting requirements and inherent difficulties, does not seem defensible. In April 1983, an agreement was made to transfer the present registry to the State fire marshal's office.

During the time that mandatory reporting of burns was first under consideration (1972-73), a variety of uses for the reports was envisioned. Among these uses were long-range planning for burn-care facilities, evaluation of burn-prevention programs, identi-

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fication of new or recurring burn hazards for investigative followup, and the publicizing of burns as a serious public health problem. Although the registry provides more data about the incidence of burns in Massachusetts than were previously available, it is not achieving any of the objectives envisioned when the project was under consideration, in part because of the difficulties outlined.

In our judgment, continuation of the present burn-reporting system in Massachusetts cannot be justified. It may be that changes in the reporting requirement or in the method of reporting would improve the registry enough to warrant its continued existence. Following the example of the California Burn Registry and the National Burn Information Exchange (a national burn registry located in Michigan), it could be stipulated that only burns involving hospitalization are reportable occurrences or, alternatively, the method of reporting might be changed from a census of all reportable burns to a sample of them. Regardless of any such changes, monies to operate the registry, including monies to collect and verify data, would increase the registry's opportunity to contribute valuable information about the epidemiology and control of burns in Massachusetts.

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